



Approved 12/03/13

**MINUTES OF THE OCTOBER 8, 2013 MEETING OF THE  
PATIENT CONSENT PREFERENCES & DATA SECURITY WORK GROUP  
OF THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY BOARD**

The Patient Consent Preferences & Data Security Work Group (Work Group) of the Illinois Health Information Exchange (ILHIE), pursuant to notice duly given, held a meeting at 2:00 p.m., on October 8, 2013, at the Bilandic Building, Suite N-700, 160 N. LaSalle, Chicago, IL; with telephone and webinar conference call capabilities.

<u>Members Present:</u> <b>Peter Eckart</b> (Co-Chair), Illinois Public Health Institute <b>Harry Rhodes</b> (Co-Chair), American Health Information Management Association	<u>Members Present:</u> <b>Colleen Connell</b> , American Civil Liberties Union <b>Elizabeth McKnight</b> , Alliance of Chicago and Chicago Health Information Technology Regional Extension Center <b>Chuck Cox</b> , MCHC/MetroChicago HIE
<u>OHIT/ILHIE Authority Staff Present:</u> <b>Raul Recarey</b> <b>Ivan Handler</b> <b>Krysta Heaney</b> <b>Ola Oni-Fatoki</b> <b>Beth LaRocca</b> <b>Kerri McBride</b> <b>Daniel Procyk</b> <b>Cory Verblen</b>	<u>Members Present by Phone:</u> <b>Julie Kovacin</b> , Lutheran Social Services <b>Jeff Swim</b> , DuPage County Health Department <b>Christine Freeman</b> , Pillars Community Services <b>Steve Lawrence</b> , Lincoln Land HIE <b>Mikki Pierce</b> , Atrium Advisory Services <b>Patricia Joseph</b> , Prospex Information <b>Morris Rang</b> , Blessing Hospital <b>Jud Deloss</b> , Popovits & Robinson <b>Satyender Goel</b> , Chicago Health Information Exchange Regional Extension Center <b>Crystal VanDeventer</b> , Lincoln Land Health Information Exchange/Illinois Health Exchange Partners <b>Victor Boike</b> , MCHE/MetroChicago HIE <b>Dana Crain</b> , Southern Illinois HIE

*Call to Order and Introductions*

Mr. Peter Eckart, Co-Chair, confirmed the presence of the members and welcomed the participants to the Work Group. Mr. Eckart facilitated brief introductions, confirmed the ability of the Work Group Members participating by telephone to hear the proceedings, and called the meeting to order at 2:00 pm.

*Approval of Minutes*

After a correction in the spelling of a name, the minutes from the meeting on September 10, 2013 were approved as submitted.

*Technical Presentation*



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Mr. Ivan Handler, CIO of ILHIE, provided an overview presentation on the technical services offered by ILHIE. Generally, under current ILHIE consent management policies, patients have a right to Opt-Out on an “all-or-nothing” basis. In addition, providers must present patients with meaningful disclosure, including information on ILHIE and the ILHIE Opt-Out policy.

Mr. Eckart asked if technology was the reason that there is not a segmented Opt-Out policy. The question was discussed among participants.

Mr. Handler proceeded to explain ILHIE’s technical approach in more detail. An independent web service will enable patient Opt-In/Opt-Out “flag” setting via technical means. Currently, the “flag” is determined through the provider; however, in the future, independent patient consent requests may utilize web applications. At present, one obstacle is finding the most effective way of verifying patient identity. Another major obstacle is specially protected information. Governed under a series of Illinois and federal laws, specially protected health information presents considerable complexity, requiring special consent for certain types of health information.

In accordance with State law, ILHIE’s standard policy is for patients to be onboard by a provider as opted in, unless the provider holds specially protected health information for its patients. Patients with specially protected information will be opted in in accordance with the standard policy only if the provider has the ability to withhold the specially protected health information prior to onboarding with the ILHIE. If the provider cannot withhold the specially protected health information, the provider must opt the patient out. Additionally, ILHIE will keep patients opted out until the provider has an opportunity to provide meaningful disclosure at the provider’s request. Mr. Handler emphasized that the patient has ultimate control over whether or not he/she participates in ILHIE. Ms. LaRocca clarified that meaningful disclosure would be given with each new provider/entity and that the patient’s “last in time” consent flag decision controls the overall consent status for a particular provider.

Next Mr. Handler discussed and defined the following elements of ILHIE:

- MPI – Master Patient Index used for cross referencing and identifying patients,
- HPD – Provider Directory used for identifying providers and Direct addressing,
- RLS – Record Locator Service used to discover records for a patient and return an aggregate record to a provider.

Mr. Handler discussed a hypothetical Use-Case showing how clinical records flow through ILHIE using the C32 Continuity of Care Document. Mr. Handler stressed to the group that ILHIE is a conduit, and is not being used as a health information repository.

Mr. Handler also spoke about the significance of the audit trail and how SAML, a standard Web protocol, is used to both authenticate users and allow for a single sign-on. Entities connecting to ILHIE are required to support SAML by June 30, 2014.

The Public Health Reporting functions of ILHIE were discussed. IDPH has established a Public Health Node (PHN) that collects reportable conditions, immunizations and syndromic surveillance data. At present, providers submit these reports via ILHIE through a dedicated connection/virtual private



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network (VPN), ILHIE Direct (secure e-mail), or secure file transfer protocol (SFTP). In the future, ILHIE expects many of these processes to function as automated systems.

Mr. Harry Rhodes recommended that the group would benefit from a presentation from SAMHSA. He also offered to contact the VA for a presentation on data segmentation for privacy, involving HL7.

A “policy vs. technology” discussion ensued and Mr. Handler reiterated that although the technology may not exist yet, ILHIE’s strategy is to develop a policy, evaluate the policy for technological feasibility, and then let the technology catch up, if needed.

### *Persona Development*

Ms. Colleen Connell, Executive Director at the ACLU, began the discussion by suggesting a “reproductive rights” persona based on an abortion scenario. She expressed concerns that when such data is entered into ILHIE, personal information that is otherwise kept private would become available to all treating providers, creating unwanted individual privacy preference sensitivities. In abortion situations, instances involving minor pregnancies, incest, domestic violence, and law enforcement are often intertwined with reproductive health information and consequently, this particular use-case deserves close scrutiny.

Mr. Handler recognized the sensitivity of the issues discussed and emphasized that the Patient Consent Preferences & Data Security Work Group was primarily focused on navigating many of the issues through a technological solutions approach; consequently, many solutions, such as patient and provider education, although still relevant, are more appropriate for other Work Groups. Generally, many of the problems revolve around preventing people, other than the treating provider, from accessing or finding out about certain types of health information; as such and in light of the Work Group’s directive, the Work Group should focus on how to limit health information to appropriate clinical use through innovative technological solutions.

Mr. Eckart asked the group to help with writing and creating personas for discussions and analysis. Due to her expertise and familiarity with reproductive rights and HIV issues, Ms. Connell volunteered to create both write-ups.

### *Public Comment*

One participant requested a way to view the technical presentation. She was told that the power point and/or webinar presentation would be made available on the web.

### *Next Steps*

The next meeting is scheduled for November 5, 2013. Mr. Eckart stated that the group would hear another technical presentation and would attempt to develop another persona.

It was suggested that in addition to discussing “breaking the glass” issues, a future list of items, ripe for discussion, should be developed.



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*Adjournment*

The meeting was adjourned at 3:26 p.m.

Minutes submitted by:

Dan Procyk, Esq.

Reviewed by Krysta Heaney and Elizabeth LaRocca